BATTEN DISEASE
Support and Research Association

THE ILLUMINATOR

Volume 25, Number 3 | September, 2014

HIGHLIGHTS OF WHAT'S INSIDE

OUR STAFF

Margie Frazier, PhD
Executive Director
800/448-4570, ext. 11
mfrazier@bdsra.org

Julie C. Conry, MA
Senior Director of
Advancement and Outreach
800/448-4570, ext. 14
jconry@bdsra.org

Becky Hetteberg, MA/LISW
Family Support Officer
800/448-4570, ext. 12
bhetteberg@bdsra.org

Tracy Kirby
Administrative Manager
800/448-4570, ext. 13
tkirby@bdsra.org

1175 Dublin Road
Columbus, Ohio 43215
800/448-4570
866/648-8718 (Fax Toll Free)

Camp Columbus Family Conference Blends Learning and Inspiration

Camp Columbus 2014, held at the Columbus Airport Marriott, was the largest family conference to date, with 406 people who traveled to the Buckeye state for reunions, group trips, and programs.

The phenomenal volunteer help from chapters, families, and friends, created an environment for learning, inspiration, and adventure. High ratings were received from those who attended this year's presentations on research, care management and personal stories on life with Batten disease.

(continued on page 2)

IN THIS ISSUE:

Ellie Benroth shares her family's quest for answers in the Batten disease journey and the philosophy they found when their world changed forever.

Read more on page 8

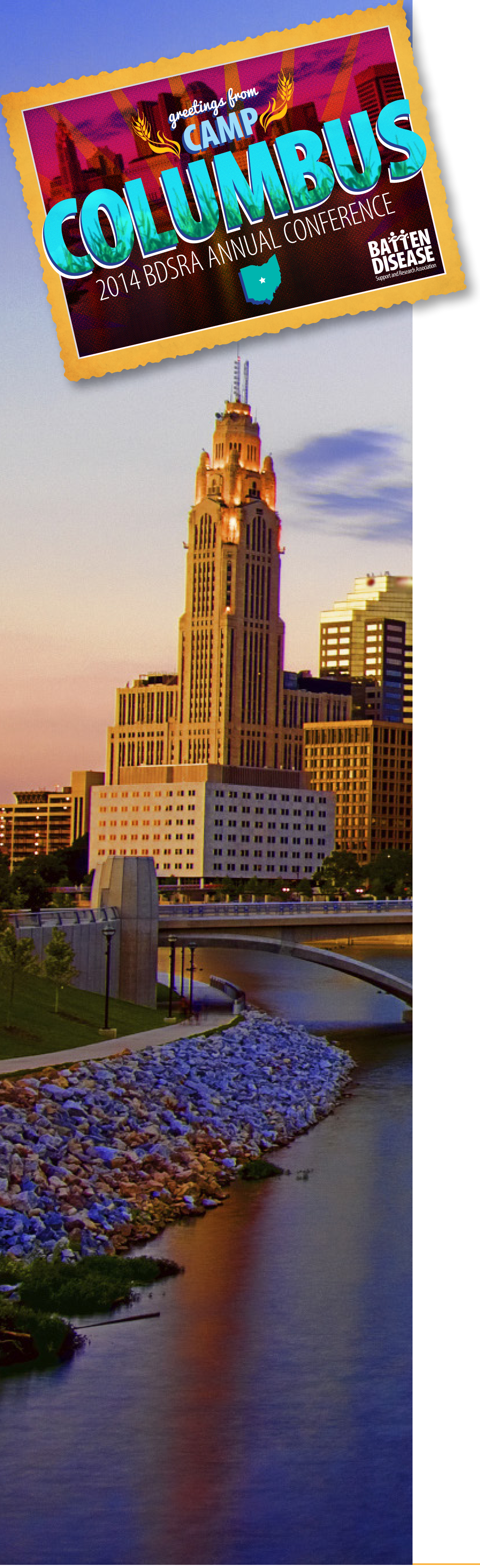
A meeting of minds and hearts. In her own words, Ramee Larson describes how the family conference brought questions and answers to parents and children alike.

Read more on page 6

One boy's long held dream is realized when the offer came to step into the announcer's booth.

Read more on page 10

www.bdsra.org facebook.com/bdsra twitter.com/bdsra



(*continued from the front cover*)

On Friday morning, the opening plenary session was a moving and emotional experience led by Ellie Willer Benroth. Her journey with Batten as mom to Kate, who has CLN2, was shared with insight, honesty, and humor. Dr. Tammy Kielian, Professor of Pathology and Microbiology at the University of Nebraska Medical Center and aunt to Olivia, who has CLN3, spoke of her path as a researcher, mom and aunt. As a researcher in neuroscience and immunology, Kielian shifted her focus to Batten disease after her niece's diagnosis to 'give her all' in helping to unlock mysteries that chain patients with Batten disease to unfulfilled destinies. The findings from the recently completed Batten Family Survey were also highlighted by Executive Director Margie Frazier, with discussion of future paths for care and discovery.

Saturday featured the annual research summaries, with state of the science updates, a poster session, and informal discussion with medical and scientific committee members. The information marketplace provided chapter news, family support information, equipment exchanges, and vendor tables.

SIBS programming included outings to the COSI science museum and Magic Mountain, fantastic art projects, and the always spirited DJ dance. The Life Goes On group traveled to the Franklin Park Conservatory and reconnected with informal gatherings, as members also served as mentors to new families.

Conference attendees also viewed a new BDSRA video, featuring families sharing their thoughts and reflections on what the family conference means to them. To view the video, go to http://bit.ly/1wsHZt0

Watch the BDSRA website and Facebook page for conference updates beginning in 2015.

Camp Columbus 2014 by the Numbers

42

kids and 1 courageous adult with Batten appeared in the Kid's Parade

75

SIBS made a big splash

1st

first pitch thrown and 9 players announced by Nora and Clifford at the Columbus Clippers baseball game

1000+

meals eaten together

1

Miss Ohio gave out door prizes

6

therapy dogs visited

128

pieces of the research puzzle donated through samples, assessments or surveys

Hundreds of memories made

Dozens of new friendships formed

10

first-time families

406

Attendees

Save the Date

Mark Your Calendars for the BDSRA Family Conference 2015

Where:

Chicago, Illinois
The Eaglewood Resort and Spa
1401 Nordic Road, Itasca, Illinois

Dates:

July 9-12, 2015

www.eaglewoodresort.com

GLOBAL RESEARCH AND STUDY UPDATES HIGHLIGHTED AT FAMILY CONFERENCE

Batten disease researchers, physicians, and scientists from academia and industry provided grant updates, progress reports, and posters during the four-day BDSRA Family Conference in Columbus. Parents and families had opportunities to speak one-on-one with researchers and many participated in ongoing studies with the study teams who were on-site.

During the plenary session Friday, Tammy Kielian, PhD, professor of pathology and microbiology at the University of Nebraska Medical Center, provided insights into her current research in juvenile Batten disease. For Kielian, an accomplished immunology researcher, the focus on Batten emerged shortly after her niece was diagnosed with JNCL in 2011. With initial funding from BDSRA, her lab pursued work with mouse models which has resulted in a significant NIH grant to investigate two classes of drugs that may delay the path of JNCL.

Saturday's State of the Science program featured updates from Jonathan Cooper, PhD, professor of experimental neuropathology at King's College London, Susan Cotman, PhD, assistant professor of neurology at Harvard Medical School and assistant in neuroscience at Massachusetts General Hospital, and Sandra Hofmann, MD, PhD, professor of internal medicine, molecular genetics, at the University of Texas Southwestern Medical Center in Dallas.

Jessica Cohen, MD, of BioMarin, provided information regarding the trial of an enzyme replacement therapy for LINCL taking place in Europe, and Jonathan Mink, MD, PhD, of the University of Rochester, gave a status update regarding the ongoing trial of mycophenylate (CellCept) as an immune-modulation therapy approach to JNCL.

Study teams from Columbus' Nationwide Children's Hospital, Sanford Research Center at the University of South Dakota, Massachusetts General Hospital, the University of Rochester, and the New York Stem Cell Foundation had representatives at conference who worked with nearly 120 individuals participating in studies, surveys, and research. The team leaders indicated it was the highest number in years of volunteers and families seeking involvement to advance the science and research related to all forms of Batten disease. The projects ranged from sleep study surveys, DNA and carrier testing, iPS cells, drug discovery, health and behavior assessments, and natural history studies.

Tammy Kielian, PhD

Batten Projects Featured in Poster Session

At the conference research open house and poster session, investigators were available to explain their projects and answer questions. Posters were created that were designed to be accessible to those without science backgrounds, and provide a basis for understanding concepts such as gene therapy, animal models, and enzyme replacement therapy.

Selected conference posters can be viewed at: **www.slideshare.net/BDSRA**

FAMILY NEEDS ASSESSMENT ANALYZES CARE ISSUES AND NEEDS

The first phase of a comprehensive family needs assessment of those involved in Batten disease caregiving was completed this spring by BDSRA with assistance from graduate students from the University of Maryland-Baltimore School of Social Work.
The survey is part of the continuing efforts of BDSRA to better serve families, invest in meaningful programming and share successes with donors.

Dr. Karen Hopkins led the student team through her course on program planning and assessment. Ninety-three (93) of our families completed a 120-question survey on-line. A second student team interviewed six families whose children have Batten disease to obtain in-depth qualitative snapshots of their day-to-day challenges. The findings are already being incorporated into programming and the annual conference.

Highlights of the survey results:

Who answered the survey?

86% were Women

70% were between the ages of 35 and 55

95% were Caucasian

70% have post-high school education

16% have graduate degrees

39% are married/civil union, 20% divorced

90% U.S. citizens

10% Canadian citizens

What form of NCL?

14% Infantile/CLN1
33% Late Infantile/CLN2
42% Juvenile/CLN3
11% CLN5, CLN7, Unknown

Ideas from Parents on how BDSRA can help:

- Help with dealing with behavior problems at home and school
- More state-by-state information on government services and resources
- Consultation and guidance on end-of-life decisions
- Assistance through an emergency fund

Those who completed the survey indicated they prefer information via email, social media and mailed information. Approximately 68% are satisfied or very satisfied with the content and quality of the information provided through the national office.

Most favored BDSRA programs?

- Private family Facebook page
- Annual Family Conference
- Teach and Be Taught Series
- Sibling carrier testing program

To read the Powerpoint presentation with more details about survey results, go to: **http://bit.ly/1maE5Vl**

In Her Own Words: Conference Memories

By Ramee Larson

Dan Moore, Nora, and Braden

We just returned home from a four day weekend in Columbus, where my dad, the kids and I attended our first BDSRA annual Family Conference.

My dad wanted our family to attend last year, but we had just returned from our Make-A-Wish trip, I was venturing my way through a divorce, and I just didn't think I could emotionally muster the courage to try at that point.

Even this year, it took a little persuading to really convince me. I needed it. Mabel needed it. And Nora and Braden needed it. So I paid our registration, even though I still felt hesitant. It's so much work to do anything with three young kids, let alone with Mabel and all of her care. Being away from home is just a challenge, and it can be overwhelming.

I knew in my mind what to expect at the conference. I was prepared to meet the families who carried me through so many dark days in this journey.

There is so much to say about this weekend. From the moment we got to the hotel and I started to see familiar faces, I was in complete awe. Mostly of the strength and courage that my fellow friends exuded. There was so much to do, so many people to see, so much to learn and a lot to take in. I have felt many things in my lifetime, but the way that I felt this weekend was entirely new.

Feelings of acceptance, unification, sadness, triumph, bravery, grief, and hope joined all of us as we walked through the days together. One thing that I walked away from this conference understanding even better than before is that this disease is a distinct journey and distinct process for everyone who is battling it. There are different phases of that journey and it looks different in each of us.

I listened to moms talk passionately about their efforts to find the exact mutation that is causing their child's symptoms. I watched mothers cry as they spoke of the compassion our children are teaching the world and at how unfair that felt, even though it was a blessing. I sat with parents whose children left earth for heaven and I saw them laugh, eat, cry, and hug with deep gratitude for life and appreciation for their children and the love they have for them.

In it all, in each of them, I still saw joy.

While most families are taking summer vacations to the beach, boarding a ship for a cruise, or just staying home to enjoy one another, I was loading my father and children into a car to experience the most life altering four days of our lives.

My children's path isn't like others. And this weekend I was able to show them that they are not alone and it is OK. They connected with other families whose lives look very similar to ours, from tube feeding to wheelchair pushing, to suctioning. They made friends with girls and boys who have lost a sister or brother to this disease. On their faces, I saw hope. Comfort. Ease. And joy.

The weekend was incredibly special for many reasons, but more than anything I am grateful that we attended for Nora and Braden's sake. They walked away having learned a lot, having made new friends and having the honor of throwing out the first pitch at a really amazing baseball game on behalf of their sister and BDSRA.

These memories are etched on my heart forever and that's worth more than I can ever express.

I came home understanding more about what this disease is overall and what I learned is this: It looks different in every single person that it affects. It takes a different course and follows no direct path. There is no warning, no clear indicator and no user's manual for Batten disease.

It was eye opening and truly inspiring to see the ease with which these children are loved and cared for.

I also came home with an extreme, deep pride for my older children. They are brave, knowledgeable, mature and very wise. It excites me to know that Mabel will help create in them a world that is full of strength, independence and compassion. Their life is different than most, but it is their normal and they have already accepted that.

Nora and Braden proudly pushed their sister in an emotional Kids Parade Saturday night. I was moved by the beauty of it all. There really are no words for how incredible these children are.

When it was time to leave, I felt an overwhelming sadness. It's just hard to come back to reality. Life outside of our little Batten island was still happening.

I'm so grateful to have had this opportunity. I'm so thankful I got to share it with my dad. We talked through many things and I think we both walked away with a lot of peace.

Saturday night Nora said to me that all of the talk about Batten disease was making her sad. I hugged her tightly and said "me too, Nora, I understand." It made me feel like I'm doing a good job at not making this disease the center of her world. I pray every day that there would be a good balance for these kids. I want their lives to be full of happy childhood memories and not consumed every day by the heaviness that has, at times, taken over my heart.

It helped me realize that I don't just 'feel' happy lately. I really have been. I really am. And they feel that. So as we move forward every day in this journey, I hope that there continues to be a balance for all of us.

One Family's Quest for Answers in the Batten Disease Journey

Ellie Benroth was one of three keynote speakers opening the annual BDSRA Family Conference July 25 in Columbus, Ohio. As mother to Kate, diagnosed with late infantile Batten disease, and her sister Lauren, and wife of Brock, Ellie shared her family's story of responding to the life changing diagnosis and the choices that followed:

"Your child has Batten disease."

Those are the words I heard as I sat in my office on June 22, 2010. For a brief moment I was relieved to have a diagnosis. We finally had an answer! Now, how do we treat it? When will my daughter be better? The moment of relief was quickly replaced with devastation and fear. How could this be? How could our daughter be dying? How do we face another day knowing her life will be cut short and her time left on earth will be filled with doctor appointments, pain, and darkness? How do I tell my husband and Lauren?

The days after Kate's diagnosis are a blur. I remember telling myself to breathe because it no longer happened voluntarily. I didn't know how to get out of bed, go to work, or take care of the house. What was the point of doing these things? Kate was dying. I needed to hold her. I needed the world to stop and let me catch my breath. I needed the world to stop so science could find a way to save my daughter's life before she progressed any more than she had. I needed the world to tell me how to live with this diagnosis and how to live without my daughter.

The day we learned our daughter had Batten disease, Brock and I decided we needed to do two things. First, we needed to make it through this journey together. We weren't going to allow this disease to destroy our marriage. Not just for our benefit but for the benefit of our girls. They needed us. Their needs were vastly different, but equally important. Second, we had to live. We had to create memories and make the most of the time we had as a family of four. That was so easy to say, but so hard to do when we felt like we were dying. How do you live when you are grieving what is, what should be and what won't be? How do you live when you see your dreams slipping away?

For Brock and I, we learned to live by embracing our faith. By trusting that the journey we were on as a family is the path we were meant to take. While we felt alone, scared, and unsure of what was ahead, we were not alone. Believing that God's plan is greater than ours and that He will be our strength, our guide, our protector and our daughter's healer, has allowed us to step out of the darkness of this disease and find joy, hope and peace. I understand we all walk different paths and we all seek strength and peace differently, but for us, our faith has been the foundation that has kept us strong.

When Margie and I discussed what I should speak about today, she mentioned talking about the joys and challenges of Batten disease. Joys, that's easy, challenges well, those are harder for me to list. The challenges should be glaring and in our face, and the joys should be hidden behind all of those challenges. However, we don't focus on the challenges. I try to list my blessings every day. Our daughter is still with us, she is able to smile, we can hold her, she has remained healthy.

The challenges of working with insurance companies, government, and finding doctors who see the value of your child and value your input are enough to make you crawl into a corner. Watching your child lose her abilities and become trapped in body and mind, never feeling their arms around your neck or hearing them say mommy or daddy again are heart breaking. And the obvious challenge of watching children earn their angel wings is the hardest part of this disease. It is so easy to let these things consume you if they are your focus.

This is why we, as a family, focus on the joys. This disease gives you permission, and almost forces you, to slow down. Most people in our society are over obligated, driven by things of this world that don't offer true fulfillment. When you are told your child's life will be cut short, you are given a pass to slow down, enjoy the moments you have. You reevaluate how you want to live.

The joy of seeing siblings love each other unconditionally is priceless. This disease teaches the "unaffected" kids so many valuable life lessons, lessons they likely wouldn't experience without having a sibling with Batten disease. Watching Lauren participate in Kate's care is one of our great joys. Their bond is a gift and one that I know without a doubt wouldn't exist if Kate wasn't sick.

This disease connects communities. People go out of their way to help those in need. They attend benefits, run 5Ks and genuinely care about our children. They often feel lost for how to help or what to do. While the disease is devastating, it has a way of bringing out the best in those who learn about it.

Our Batten family has been like a life raft. We felt like we were sinking and alone and then we found the Facebook group and all of the sudden we weren't alone. Yes, we had our family, friends and church family, but at the end of the day they can't understand what it is like. To watch your child deteriorate, to make the decisions we make every day and to know that without a miracle, we will have to say good-bye to our child. When you live in a small community and you are one of two families with a child with severe disabilities, it can be lonely.

I resisted meeting Batten families for many months after Kate's diagnosis. Maybe because I felt like a group of strangers couldn't comfort or support us, maybe I was scared to see the kids knowing that Kate would one day endure what others were already living with. Whatever my reasons were, I am so thankful for our Batten family. We look forward to this weekend every year. Knowing we are all fighting the same fight, brings peace. We are thankful we have each of you to share this journey with. To share our ups, downs, joys, and challenges. We are thankful you share your journey with us and allow us to love your children.

Columbus Clippers Deliver a Dream for Guest Announcer

Friday, July 25, 2014 was a memorable day for the Dahl family of Chatham, Illinois. Parents David and Corrina, and their sons Clifford, 17, and Isaac, 12, set out not just to attend a minor league baseball game at the Huntington Park in Columbus. Their quest was giving Clifford the chance to realize a long-held dream – to be a sports announcer.

For most kids, this idea would not be an impossible achievement. For Clifford, diagnosed with JNCL, his passion for baseball and sports has always been a joy, something his family has nurtured. They've never let Batten disease limit his dedication to all things baseball. This was one night when the stars would align and he would be part of it.

Clifford's mom Corrina was thrilled he would be able to announce the players coming up to bat in the second half of the Columbus Clippers baseball game, during an outing of the BDSRA Family Conference.

"This was a dream come true for Clifford, who has loved sports, especially baseball since he was a baby," she said. "He attended his first baseball game, the Peoria Chiefs, when he was just three months old and he would sit with his father and watch baseball on TV every day that they could."

"We are a radio family, with Clifford's dad being a reporter and anchor on the radio. Clifford got a radio in his room when he was a toddler so he could listen to baseball and other sports whenever he wanted," she noted.

"When he lost his sight, listening to the radio became even more important, and he would take a radio headphone set to games so he could hear the broadcast and know what was happening on the field. His favorite team is, of course, the St. Louis Cardinals. However, he loves baseball so much he will listen to any team anywhere and loves to attend games whenever he can."

Corrina notes, "anyone who meets Clifford for the first time quickly learns what a baseball fan he is because he usually asks people what their favorite team is."

When BDSRA conference planners set up the group trip to the baseball game, executive director Margie Frazier knew just who to call about helping out in the announcer's booth. "When we learned there would indeed be a game, Margie asked me if Clifford would like to announce. I told her I knew that he would," Corrina recalled.

The anticipation and excitement for the Dahls was immense.

"We decided to not tell Clifford until the day of the game. We wanted it to be a surprise. He was very surprised and excited," she said. "He loved going onto the field and meeting the players and the mascots. He loved going into the sound booth and meeting the announcers and most of all he loved announcing the players."

It was a moment that was 17 years in the making, according to his mom.

"You see, when Clifford was little he loved playing baseball and like many little boys he imagined being a ball player when he grew up," she explained.

"Losing his eyesight, he realized that would not happen for him, but he never complained, he found a new dream, to be a baseball announcer."

With his dad as his assistant, Clifford climbed up to the broadcast booth at the stadium and proudly called the player names for the batting order. It's a moment his family will never forget.

"When he returned to his seat, he looked at me and said 'I'm a real announcer now,'" she noted. "He was so thrilled and proud, it brought me to tears to see him so happy and to know that for him, his dream was fulfilled."

www.bdsra.org

Have you liked
us on Facebook?

Followed us
on Twitter?

Find us and
join the BDSRA
conversation online!

facebook.com/bdsra

twitter.com/bdsra

BDSRA Announces Board Nominations for November Elections

The BDSRA Board of Directors will have four available seats beginning January, 2015. The board and staff seek individuals who are motivated by the opportunities and challenges of fundraising and resource development, governing, research, and outreach to families.

BDSRA Board Service Basics:
Terms are 3 years, and board members must be paid dues members of BDSRA.

By-laws indicate that 60% of the board must be comprised of a family member of an affected person. Board members may serve consecutive terms.

Board members are required to attend 2 meetings in person each year and are responsible for paying the associated costs for transportation, hotel and meals. One meeting is held during the winter and one is scheduled the day before the annual family conference in July.

Other meetings are held by conference call, approximately four times a year.

Board members with marketing and communications, fundraising, social media, finance, business, accounting, and medical skills are sought at this time.

Most important to BDSRA is the passion for our work on behalf of families, strong support of staff, and active advocacy and outreach efforts to tell the BDSRA story.

Anyone who is interested in running for a position on the board must contact board member Tony Ferrandino, at tonykatie@comcast.net by October 15, 2014. Prospective board members are required to complete a personal fact sheet for the election ballot and return them via email to Tony by October 22, 2014.

Voting ballots to all current, paid BDSRA members will be mailed by October 27, 2014, and must be returned via U.S. mail to the accounting firm collecting the ballots by November 15, 2014.

A reminder about paying BDSRA member dues:

According to the bylaws of BDSRA, ballots will be mailed only to those who have paid their 2014 membership dues as of October 15, 2014. Can't remember if you've paid your dues? Please email Tracy Kirby at tkirby@bdsra.org to inquire. Dues may be paid online by visiting www.bdsra.org, clicking on the link "How to Help," and choosing the annual membership link in the drop down box. A membership dues form will appear from the link that can be completed along with a credit card payment. Each paid membership has one vote in board elections. Dues are $40.

Staff and Board News

BDSRA Executive Director Margie Frazier has accepted a volunteer role to serve as the Lysosomal Disease Network (LDN) Council of Patient Advocates (COPA) group leader. There are 30 patient advocate groups in COPA, who link with LDN to advance the research and science of rare disorders. The group leader facilitates communication between the council, LDN, and the National Institutes of Health.

BDSRA board members Tracy VanHoutan and Tony Ferrandino provided testimony to the FDA in Washington, D.C. on June 10, 2014 during the public meeting on Inborn Errors of Metabolism. They spoke to the panel about the patient and caregiving challenges facing families. The FDA forum was designed to obtain direct feedback from patients and advocates regarding specific diseases and conditions.

BDSRA staff member Julie Conry has joined the editorial board of the Patient Engagement Community (PEC) of the Drug Information Association (DIA) and is co-chairing a Whitepaper and PEC publications committee for the PEC. The PEC is focused on bringing the patient voice and patient perspective to decision makers and leaders in the pharmaceutical and drug industry.

Dr. Chris Leonard has departed BDSRA and accepted a full-time position with SRA International as a Manager working on the Congressionally Directed Medical Research Program (CDMRP) peer review contract for the Department of Defense. CDMRP oversees the administration of several hundred million dollars in military-related, peer-reviewed medical research appropriated in the DOD budget. We wish Dr. Leonard the best of luck in this new professional opportunity.

BDSRA Board Convenes July Meeting

The BDSRA board of directors convened its day-long meeting in Columbus prior to the annual conference. A new slate of officers was elected: Rob Geer, president, Tracy VanHoutan, vice president, Mike Collins, secretary and Joel Karg, treasurer. At the meeting the board bid farewell and thanks to Kim Zellmer, who served for three years as BDSRA president. Those whose terms also expire at the end of 2014 are Chris Lowden and Chris Hawkins.

Research was a main focus of the meeting, with the board voting on the process for the next RFP cycle. BDSRA has had good success within rare disease groups in moving science to the clinical trial phase by investing in the tools necessary to build platforms for inquiry, such as registries, human and animal samples, and basic biomarkers.

The board voted to structure the 2014 cycle by instituting a Request for Letters of Intent (RLOI) to be open on Oct. 1, 2014. Letters of intent will be reviewed and requests for full proposals to be peer reviewed will be made in January, 2015. Awards will be announced at the annual conference in Chicago.

There will be four open positions on the board in the upcoming fall election. Nomination forms for board service may be submitted in October. During the discussion of board service, members voted unanimously to allow the board to appoint up to two members to open board seats for two-year terms to fill key roles needed by the organization—primarily legal and CPA professionals.

BDSRA Board members:
(first row left to right): Barbara Wuebbels, Kim Zellmer, Mike Collins and Margie Frazier;
(second row l to r) Tony Ferrandino, Rob Geer and Christopher Lowden;
(third row l to r) Dave Pearce, Chris Hawkins, Tracy VanHoutan.

BDSRA Opens RLOI for 2014 Funding Cycle

The board of directors of BDSRA has approved a 2014 RLOI schedule for the 2014 research grants. On October 1, 2014, BDSRA will issue an open call for Letters of Intent (LOI) for grant projects related to Batten disease. The LOI should describe proposals of innovative research that have the potential to advance therapeutic strategies for all of the Neuronal Ceroid Lipofuscinoses. Each award, depending on funding availability, will be no more than $60,000 over a one-year period.

Letters of intent must be submitted by November 15, 2014. The LOIs will be reviewed by members of the BDSRA board and invited scientific reviewers. Requests for full proposals that will be peer reviewed will be made in February, 2015. Awards will be announced mid-year.

Further details regarding the process and submission deadlines will be posted on the BDSRA website at www.bdsra.org.

SCHOOL DAYS OR SCHOOL MAZE?

As the heat of summer gives way to crisper fall days, attention turns to a new school year. For parents, it's not unusual to experience mixed emotions as affected and non-affected kids return to the classroom. Everyone is glad to see familiar faces and get into a routine again. But transitions can sometimes create new concerns when there are moves into new settings and new school personnel. As the BDSRA "Teach and Be Taught" manual states, "a challenge awaits you."

Parents strive to obtain the best education for their affected children so they can experience the best quality of life possible, despite limitations from Batten disease. A team approach is often the most effective pathway, and the national office is here to support and help with resources for problem solving and education.

At BDSRA, we get inquiries from parents and caregivers about special education needs routinely. There are many common concerns, such as:

Q: I'm confused as to what an Individualized Education Plan (IEP) should include for my child -- where do I start?

Q: My child is young -- are there educational services for preschoolers with Batten disease?

Q: My school isn't following the IEP that we set up for my child -- what should I do next?

Q: My child has severe behavioral issues -- how should the school address these?

Q: I'm concerned about my child's inability to fight infection and school environments are notorious for spreading germs -- what are your recommendations during flu season?

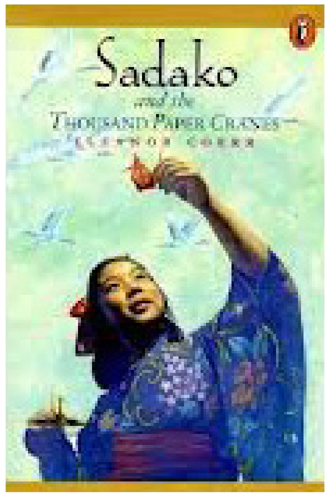
To help find answers, BDSRA's "Teach & Be Taught" series is a good place to start. This guide consists of a manual and 3 DVD's, all of which outline specifics for how to provide accommodations for children and teens with Batten disease. BDSRA also has the closed Facebook group for parents and caregivers. In the group, questions or concerns can be offered for feedback from other Batten moms, dads, and caregivers. Our Batten families are experts and can provide timely advice and tips that have worked for them.

Another go-to resource for parents is **www.WrightsLaw.com.** This website has articles, cases, and links that explain many aspects of special education and advocacy. It was created by Pete and Pam Wright: he is an attorney specializing in special education law and she is a psychotherapist who has worked with children and families for decades. Some of the site's material regarding IEP's includes questions and answers on IEP's, evaluations, and re-evaluations, the IDEA 2004 law and what you need to know about IEP's for children with behavioral problems, and resolving IEP disputes.

Other topics covered on the website are evaluations, behavior and discipline, assistive technology, and early intervention. There are also links to free flyers, publications and newsletters. As with any issue or concern, Batten families may seek assistance from the national office staff by contacting Becky Hetteberg at **bhetteberg@bdsra.org** or calling **800-448-4570**.

the BDSRA BOOKSHELF

Children's Book Selection

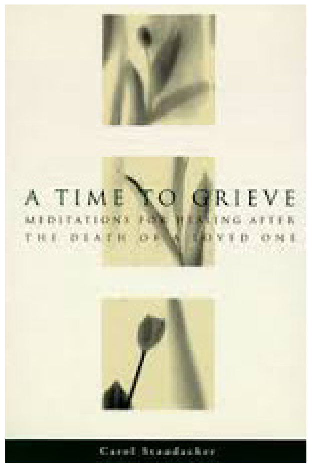


"Sadako and the Thousand Paper Cranes"

by Eleanor Coerr

Hiroshima-born Sadako is lively and athletic – the star of her school's running team. And then the dizzy spells start. Soon gravely ill with leukemia, an after effect of the atom bomb that fell on the city in 1945 where she lived when she was a baby, Sadako approaches her illness as she did her running – with an irrepressible spirit. She recalls a Japanese legend and sets out to work folding many paper cranes. The legend holds that if a sick person folds one thousand cranes, the gods will grant her wish and make her healthy again. This book is based on a true story and it celebrates the courage of a child and the kindness of her friends who helped her reach her goal of folding one thousand cranes. The paper crane is an international symbol of peace. To learn more about the art of origami or instructions on how to fold a paper crane, visit www.origami-usa.org

Adult Book Selection



"A Time To Grieve – Meditations for Healing After The Death of a Loved One"

by *Carol Staudacher*

"Some survivors try to think their way through grief. That doesn't work. Grief is a releasing process, a discovery process, a healing process. We cannot release or discover or heal by the use of our minds alone. The brain must follow the heart at a respectful distance. It is our hearts that ache when a loved one dies. It is our emotions that are most drastically affected. Certainly the mind suffers, the mind recalls, the mind may plot and plan and wish, but it is the heart that will blaze the trail through the thicket of grief." Excerpt taken from "A Time to Grieve."

This book is a collection of truly comforting, down-to-earth thoughts and meditations -- including the authentic voices of survivors. For anyone grieving the loss of a loved one, this book provides perspective and mirrors the universal experience of those who have traveled through immense loss and change. Carol Staudacher is a grief consultant, lecturer, and author of Beyond Grief and Men and Grief.

NEWS FROM OUR SUPPORTERS

PENNSYLVANIA EVENT FEATURES CHARITY RIDE

Volunteers in Mechanicsville, Pennsylvania rallied for the fourth annual Ryan Kennedy Memorial Motorcycle Charity Ride June 14, 2014 to support BDSRA. Organized by the Red Land High School Alumni Association and the Erb and Kennedy families, the event honors and pays tribute to the memory of Ryan and his cousin Chris, both of whom had Batten disease. Riders tour through York County, Pennsylvania and multiple stops are set up for raffles and prizes. Donors contributed $3,498 to BDSRA.

OHIO'S ASHER BASH BENEFIT SUPPORTS RESEARCH

The 9th annual Asher Bash benefit concert and poker- run took place July 19, 2014 in Huron, Ohio. Organizer Victor Nikolajevs, father of Asher, who has INCL, created the day-long event to continue motivating community members to support Batten disease research. Following the concert and cycling tour throughout the Huron area, $2,237 was donated to BDSRA.

GOLF TOURNAMENT IN MARYLAND GENERATES GIFTS

The family of the late Kevin Lumm and the Maugansville Ruritan Club hosted the 11th annual "Kevin's Fund" golf tournament at Black Rock Golf Course in Hagerstown, Maryland June 27, 2014. Golfers and volunteers dedicated their day to Kevin's memory and the fight for a cure, a tradition started more than a decade earlier to support the Lumm family and create a legacy for the family's journey with Batten disease. This year, $5,000 was donated to BDSRA following the tournament.

TRIVIA MATCH RAISES AWARENESS AND FUNDS IN THE MIDWEST

A silent auction and trivia night organized by the Heart of America BDSRA Chapter on February 21, 2014 generated $6,350 for BDSRA research and services. Multiple teams played 10 rounds with teams featuring themes and costumes, including chefs and other crafty groups. The winter event in Columbia, Missouri also highlights information regarding Batten disease research and advances in labs throughout the globe dedicated to basic science connected to Batten.

MINNESOTA FAMILY COMPLETES COMMUNITY CHALLENGE

The Pauling family of Montevideo, Minnesota, Jeremy and Kristy, and daughters Katelyn, Kaylee, and Kassey, organized a community challenge this spring to raise funds for Batten disease. Many businesses related to agriculture and farm owners in their community joined efforts to meet a fundraising challenge for BDSRA. More than $11,000 was donated, which the family presented at the Annual Family Conference in Columbus. Katelyn, 8, has LINCL, and her sisters are active in the conference SIBS program.

GARAGE SALE NETS SALES FOR BATTEN DISEASE

A neighborhood garage sale in Lino Lakes, Minnesota organized by the Davies family brought sales that resulted in a $1,931 donation to BDSRA. Kristine and Eli Davies and their twins Maya and Mason created the event in memory of their son and brother Ethan, who had LINCL. The Davies family and their foundation, Ethan's Reason, also sponsored the SIBS pool party at the family conference this year.

WELLNESS ADVOCATE DONATES SERVICES FOR BATTEN AWARENESS

Veronica Ramirez, owner of the Dublin, Ohio based Ascential Acupuncture, held an event June 7, 2014 to raise funds and awareness for Batten disease. She held a class about essential oils and health benefits, and donated $1 for every acupuncture treatment and a portion of sales during the month of June. Her efforts came about after learning about Batten disease from the Betz family and their late daughter Celia. Family members Rosie Tolliver, Jan Betz, and Vicky Betz participated in the essential oils class.

UNCLE DEDICATES BOSTON MARATHON RUN TO NEPHEW

Jacksonville, Florida resident Richard C. Fannin, an uncle to the late Jake Medley, also of Florida, dedicated his run in the 2014 Boston Marathon to Jake and his battle with Batten disease. Through pledges and donations committed to his efforts in the marathon, Fannin donated more than $2,000 to BDSRA in memory of Jake.

DONATE TO BDSRA THROUGH THE CFC CAMPAIGN

The fall months bring the official kick-off for the national Combined Federal Campaign (CFC) and many United Way Agency workplace campaigns. Donors to either CFC or United Way can designate their gift or pledge to Batten Disease Support and Research Association to benefit the research and service efforts underway for families with Batten disease.

For federal government employees, postal employees, military families, and state government employees linked to the CFC, making a charitable gift to BDSRA through the CFC is a simple process. In the 2014 Catalog of Caring, the BDSRA charity CFC registration number is 11781. Donors can contribute online or through a paper pledge form and designate their contribution by filling in the 5-digit BDSRA code, which is 11781. Gifts can be made through credit/debit cards, eCheck, cash, check, or payroll deduction.

To determine the CFC regional campaign locations in each state, or to request a pledge card, visit www.opm.gov.cfc and click on the link "Donating through CFC."

Those individuals wishing to direct their workplace giving through the United Way campaign to BDSRA can reach their local United Way agency by the national website www.liveunited.org. By typing in a local zip code into the search box, the website will connect donors to their affiliates in their community. Donors should identify that their gifts through United Way are for BDSRA by writing in the name of the charity on the pledge form. As a 501c3 non-profit, BDSRA is eligible to receive donations through workplace giving programs.

Gifts through affiliated campaigns are a great opportunity to support the mission of research and service and touch the lives of many children and families facing Batten disease.

BATTEN DOCUMENTARY TO APPEAR AT INTERNATIONAL FILM FESTIVAL

The documentary film "Beating Batten," has been accepted to the Life Sciences Film Festival in Prague taking place in October, 2014.


Zuzana Gedeon

Zuzana Gedeon, who wrote, produced, and directed the film, frames the documentary to tell the story of her late daughter Sara, who passed away in 2006 from late infantile Batten disease.

A Montana resident, Gedeon turned to filmmaking after losing her daughter and the project evolved from an assignment in a film class. The documentary profiles her family's challenges after Sara's diagnosis and discusses the need and urgency for research into treatments and cures for Batten disease.

Her goal as a filmmaker, she says, is to share her experience caring for a child with Batten disease and promote awareness of the disease. This opportunity is critical to take the subject of Batten disease overseas to a whole new audience to expand people's understanding of rare disease, she added.

The goal of the LSF film festival is to present and award the latest documentary films dealing with natural sciences and present the possibilities of their use in education. The festival consists of an international film competition, screening of non-competition films, lectures, and discussions.

BDSRA IS ALL ABOUT FAMILIES CONNECTING WITH EACH OTHER

Help us update the BDSRA family directory. If you would like to be included, please send your name, address, contact information and affected person's name and NCL type to **tkirby@bdsra.org**.

This information is for the directory only. BDSRA does not sell or share the directory with outside companies or organizations.

CONFERENCE SUPPORTERS MAKE IT POSSIBLE

During the final Saturday event at the 2014 annual BDSRA Family Conference, public recognition and certificates were awarded to families, friends, supporters, and BDSRA Chapters for all their efforts in fundraising and awareness building between June, 2013 and July, 2014.

Those receiving certificates were:

The Calerra Elks Lodge 2703 and Becki Lucas in memory of Chris Gaines (Corn Hole Tournament)

The Hold and Worster families in memory of Chelsey Worster (T-shirt fundraiser)

Joan Ortland and family for bracelet sale in memory of Danny Ortland

The Davies family for their garage sale in memory of Ethan Davies

The Surrey family for the Surrey 7th annual yard sale in honor of Lauren and Michele Surrey

The Lumm family for the Kevin's Fund Golf Tournament in memory of Kevin Lumm

The Melissa Froio Foundation and the Froio family in memory of Melissa (Monte Carlo night)

The Medley family for their lemonade stand and Boston Marathon run of Richard Fannin in memory of Jake Medley

The Benroth family honoring Kate Benroth (Running Toward a Cure 5k Race and Walk for Kate and Lauren's Lemonade Stand)

Victor Nikolajevs honoring Asher Nikolajevs (Asher Bash)

Lisa Boyle and the Bergram family in memory of Carl Bergram (Kick Batten's for Carl 5k Race)

The Hawkins family in honor of Brandon and Jeremy Hawkins (Our Boys Race)

The Red Land High School Alumni Association and the Kennedy family motorcycle event in memory of Ryan Kennedy and Chris Erb

The Land O' Lakes Company and Mike Mueller in memory of Casey Mueller (Mini-golf Tournament)

Friends of the Betz family in memory of Celia Betz (For Battling Batten Disease 5k and Walk)

Mike Smith for Mike's Beer Bucket Golf Outing

The O'Neill Family in memory of Meghan O'Neill (Batten Blue Print)

West Wyomissing Fire Company in memory of the Pinder children (Miles for Michael event)

Catie and Annie's Cops Relay in honor of Catie Allio and in memory of Annie Allio

Korry and Rachael Sharp Roundup 5k in memory of Korry and Rachael Sharp

The Pauling family challenge in honor of Katelyn Pauling

Chad's Hunt for a Cure honoring Chad Dovel

Buzz 4 a Cure in memory of Casen Cameron

The Lugine Hein family in memory of Austin Hein (Strawberry Fest Fundraiser)

BDSRA Chapters Honored:

The Southeast Chapter

The Tennessee Chapter

The Metro NY/NJ Chapter

The Midwest Chapter

The Alabama Chapter

The Heart of America Chapter

The Northern California Chapter

The Ohio Chapter

Co-Funders of the 2013 BDSRA Research Consortium Grants:

Noah's Hope
BDSRA Australia
Hope 4 Bridget
BDFA of the UK

CHAMPIONS ($10,000 AND ABOVE)

BIOMARIN®

ADVOCATES ($5,000 TO $9,999)

Anonymous – Saturday Lunch
Ron and Lugine Hein (in memory of Austin Hein) – Friday Lunch

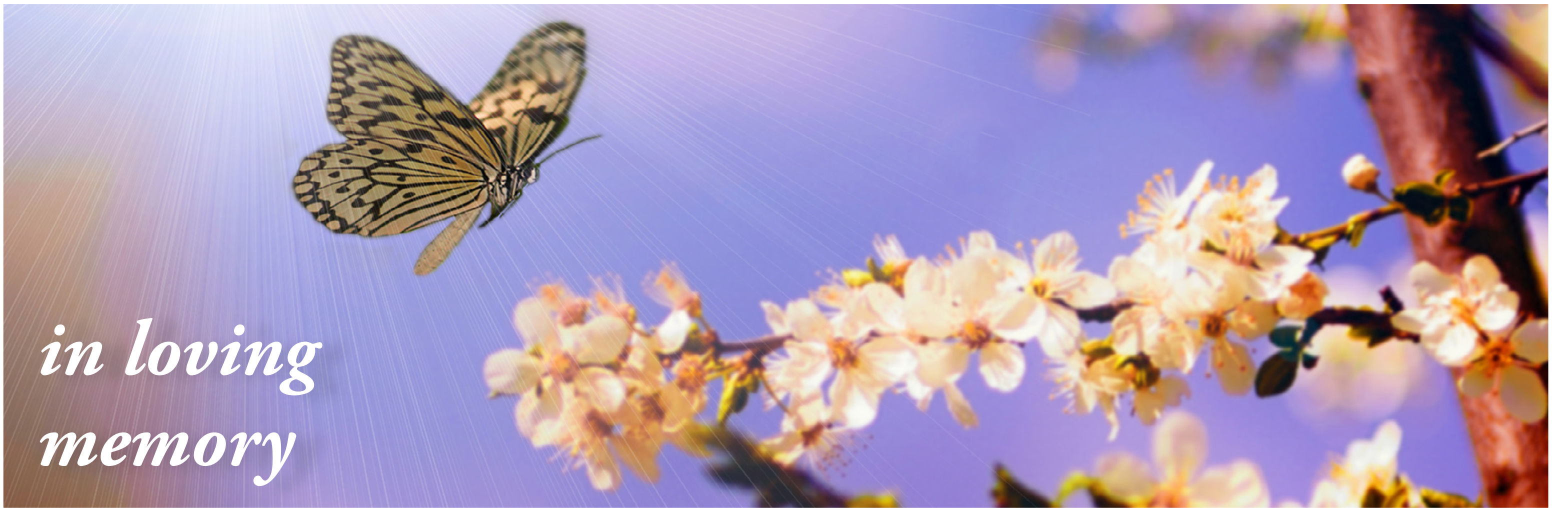
Pfizer

PARTNERS ($1,000 TO $4,999)

Anonymous
Beyond Batten Disease Foundation – Plenary Session
Drew's Hope
Gayle Holton Design – Program Design (in memory of Celia Betz)
Holding onto Kate – Sib/Parent Panel
Hope 4 Bridget/Partnership 4 Cures – Scientific Poster Session
Mary Payton's Miracle Foundation – First Time/Newly Diagnosed Session and T-Shirt Sponsor
Mackenzie's Hope – Kid's Parade
Metro NY/NJ Chapter BDSRA
Nationwide Children's Hospital – Welcome Reception and T-Shirt Sponsor
Noah's Hope/Partnership 4 Cures – Scientific Poster Session
Orsini Healthcare – Plenary Session
Sanford Children's Research Center – Sibs Programming
Southeast Chapter BDSRA – Welcome Reception

SUPPORTERS ($500 TO $999)

Burns & Wilcox – Sibs Programming
Charlee's Angels – T-shirt Sponsor
Ethan's Reason – Sibs Pool and Pizza Party
Gardner Denver Inc – Life Goes On Outing
Dave Lippert and Margie Frazier
Midwest Chapter BDSRA – Columbus Clippers Baseball Game
Ohio Chapter BDSRA – Life Goes On Outing
Tennessee Chapter BDSRA



in loving memory

REY BEN ALSEMGEEST, son of
David and Kazumi Alsemgeest,
London, Ontario, Canada
Born: 7-16-05 | Died: 8-31-14
Late Infantile

JONATHAN DAVID MCCOLLUM,
son of David and Wanda McCollum,
McLeansville NC
Born: 1-7-81 | Died: 8-18-14
Juvenile

ZICHAELA CAFFEY, daughter of
Kenda Caffey and Anthony Arteese,
Arlington TX
Born: 8-8-05 | Died: 7-22-14
Late Infantile

KANE DEGEORGIS, son of
Brian DeGeorgis and Linda Crain,
Taylors SC
Born: 1-7-08 | Died: 7-20-14
Late Infantile

SAMANTHA APODACA, daughter of
Vanessa Apodaca, Albuquerque NM
Born: 2-27-06 | Died: 6-9-14 | Infantile

KENNEDY ANN HANSEN, daughter of
Jason and Heather Hansen,
West Haven UT
Born: 11-25-97 | Died: 5-30-14
Juvenile

NICHOLAS ROBERT DAINIAK, son of
Chris and Heather Dainiak, Bedford NH
Born: 5-9-03 | Died: 5-9-14
Late Infantile

JACOB "JAKE" MEDLEY, son of
Dean and Jennifer Medley,
Jacksonville FL
Born: 9-24-04 | Died: 4-28-14
Late Infantile

DYLAN SMITH, son of
Shawn and Christine Smith,
McMurray PA
Born: 2008 | Died: 4-23-14

CASEN MICHAEL CAMERON, son of
Corey Cameron, Holly Lake Ranch TX
Born: 1-15-07 | Died: 4-23-14
Late Infantile

NATALIE ANN MARIE KUEHL, daughter
of Shane and Sara Kuehl, Brookings SD
Born: 3-2-05 | Died: 3-10-14

EZEKIAL TODD HOLT, son of
Andrew and Bree Holt, Toledo, OH
Born: 11-19-09 | Died: 3-23-14
Late Infantile

AUSTIN SAMUEL HEIN, son of
Ron and Lugine Hein, Columbia, MO
Born: 10-30-93 | Died: 3-21-14 | Juvenile

CHARLEE MARCELLA NELSON,
daughter of Jeff and Catrina Nelson,
West Jordan, UT
Born: 1-30-08 | Died: 3-15-14
Late Infantile

SKYLER JORDAN ROWE, granddaughter
of Terrie Rhoden, Argillite, KY
Born: 4-26-06 | Died: 3-8-14
Late Infantile

NOLAN HENRY JAMES LEIS, son of
Chad and Shannon Leis, Bangor, WI
Born: 5-24-03 | Died: 2-25-14
Late Infantile

CHAD ALAN DOVEL, son of
Charles and Debbie Dovel, Hamburg, IA
Born: 6-3-89 | Died: 2-9-14 | Juvenile

BDSRA takes great care to memorialize those individuals who have passed away from Batten disease. If a person is omitted from this page, it is because BDSRA was not notified of the death, did not have permission to publish, or did not have confirmed information.

SECOND AND THIRD QUARTER DONOR GIFTS

(Gifts given April 1, 2014 through August 31, 2014)

The Batten Disease Support and Research Association has been remembered many times in the past five months by families and friends affected by Batten disease. Thank you for your generous contributions. This support for the vital mission of research and services for families is crucial to finding a cure. We are also grateful to those supporters who have participated in events and volunteered their time to advance our efforts for Batten disease research and family services. We also acknowledge in this donor list all the generous contributions made through the 2013 Annual Fund Campaign.

IN HONOR OF:

THE ALLIO and SHARP FAMILIES
Daniel and Nancy Hynie

JOVAN ALLEN
Chenyl Allen

DIANE ANDERSON
Gregory and Bernadette Lis

AMY BAC
Anonymous
Christy Bac
Jessica Riley

JULIE BECKSFORT
James and Margaret Becksfort

KATE BENROTH
Cheryl Mansfield
Britt Menchhofer
Jessica Osborn

JAN BETZ
Christopher and Dana Wright

CAMERON BOLEY
Mom and Dad
Robert Butler
Mike and Tina Rawson

WILLIAM BRADDOCK
Anonymous
Karye Brockert
William Chappell
Chadd and Traci Kobielush
Morgan Roberts

KENDA CAFFEY
Michelle Killinger

NAOMI CAUGHEY
Bob and Barb Caughey

TRACY CERAVONE
Paula Perssico

ROB CHANDHOK
Beau James

SOPHIA GRACE CRAWFORD
Mom and Dad
Joseph and Jennifer Ball
Chander Bishnoi
Christina Chambers
Jennifer Cranfield-McDaniel
Gregory Ford
Victoria Griffin
Cora Hazelbaker
Marsha Kidd
Lisa Pirog
Jennifer Schlegel
Lizeth Torrico
Mary Tucker

CLIFFORD DAHL
Mom and Dad
Friends of the Chatham Library Café
Jennifer Wernsing

KENNETH DOCKTER
Ella Morro

MIKAYLAH EDENS
Rosemary Wood

ADIA ELFERT
North Coast Litho

SAM ENGMAN
April Bishop

JOHN FANNIN
George and Dorothy Dorion

RYAN FARET
Mom and Dad
Edward and Veronica Snyder
James Thomas

LEAH FITZGERALD
Valerie Johnson

KELSEY FULLER
Eric and Karen Fuller
Sylvia Fuller

ELVIS G.
Norma Alba

ETHAN GAHLBECK
Ala and Lorinda Gahlbeck
Phil and Diane Whitson

JACOB GEER
Carol Curry

KEVIN GRACZYK
Customink LLC

TRENT GRADY
Dominique Mortimer

JOSHUA GUNN
Wendy Radford

FRANK and BRIDGETTE HARRISON
Ronnie and Pearl Harrison

THOMAS HAYES
Andy and Jenni Betz

BRYLEE GRACE HOLMES
Gena Dalton

NATHAN HOOVER
Chad and Lori Ernst

JESSICA HYNIE
Robert and Patricia Hurst
Martha Skelly

SARAH INKS
William Gellerman and Victoria Thorpe
Charles Shrader

COURTNEY and NOAH JOHNSON
Dennis and Sharon Depoi

BRIDGET KENNICOTT
Robert and Jennifer Shannon

ERIC and MCKENNA LOWDEN
John and Marjorie Huff

ZACHARY KILLINGER
Keith and Stephanie Housley
David and Michelle Killinger
Michelle Killinger

MABEL LARSON
Rebecca Abrams
Tori Alexander
Janice Bergeron
Christina Day
Crissy Dixon
Cynthia Girdler
Jennifer Meschnark
Kaycie Neuhaus
Sarah Peterson
Elizabeth Sessions
Megan Smitley
Melissa Tarter
Julie Wagner-Hinrichs
Natalie Watkins
Connie Werkman
Delaina Wertz
Courtney Westlake

RAMEE LARSON
Anne Settanni

OLIVIA GRACE LEWIS
Troy and Rebecca Crochet
Melanie Dennis
Cindy B Hebert
Kendrick and Tanya Lawrence
Brody Lewis
David E Lewis
Spencer and Lisa Lewis
Louisiana Farm Bureau Credit Union
Lance and Lauren Moulin
Tamme Nolan
Jeff and Rana Reinholtz
Kevin and Gwendolyn Seeger
Susan Shaffer
Richard Traweek
Reydaishune and Jernae Weber

THE LOWDEN FAMILY
Ronald and Faith Thompson

ERIC and MCKENNA LOWDEN
John and Marjorie Huff
Ronda Kalka

EDDIE MAJESKI
Stanley Rybicki and Cynthia Curtis

BRIANNA MACMORRAN
Scott Pryne

JOHN MANGUM
Anonymous
Mom and Dad

MICHAEL METCALF
Kim and Laren Metcalf

WESTLEY MCKINLEY
Frank and Jo Webster

JEFF MONTAVON
Sarah Freiburger
Michael and Debbie Merriman
Jeffrey and Lori Simonton

JONATHAN MORTENSEN
Michael and Christine Mortensen

CARSON and CAROLYN NEIFERT and
CARSON, WILLIE and VIOLET SHERMAN
Bobbie and Gary Vruggink

BYRAN NI
Bob Ni

MARA NICK
Anonymous

ASHER NIKOLAJEVS
John and Mary Alexander
Michael and Debra Ashley
Kelly A Bukrim
Carl and Delores Davis
Michael and Dyanna Dearth
Richard and Mary Gaul
David Greiner
Jonathon Grimm
Scott and Felicia Maschari
Ann Nikolajevs
Andrew and Francine Reiber
Alan J. Rogers
Smiley Automotive
Randy and Cheryl Taylor
Gary Uther
Robert and Loriann Wagner
Jeffrey Wright

ASHER OAKES
S.S. Oakes

AMY PARRISH
Jenni and Andy Betz

KATELYN PAULING
Jessica L Anderson
Nic and Kelly Barrick
Alain and Kathern Bellicot
Douglas and Deborah Bothun
Country Care Services, LLC
Linda Dolan
David Drake
Noelle Green
Daniel and Kathleen Grzybowski
Ross Ingwersen
J & D Construction, Inc.
Justin and Marilee Jager
Dana Johnson
Diane Ketelsen
Jason J Lee
Jerome and Ruth Lee
Scott and Molly Martin
Scott and Wendie McKernan
Minnwest Casual Wear Fund
Scott and Teresa Mitlyng
Jeff and Jill Mortenson
Christopher Newton
Daniel and Sara Noreen
Oahe Grain Corporation
Dereck and Breanna Olson
Janice Olson
Pauling Homes Corp
Jeremy and Kristy Pauling
Pesco Inc.
Prairie Grain Partners, LLC
Scot and Jennifer Roth
Schlagel, Inc.
Jim and Kris Slettedahl
Justin and Beth Smith
Smitty's Garage
Waconia Manufacturing, Inc.
Warrior Mfg
Sheree Williamson

NICHOLAS PERUYERO
Anonymous

WILLIAM PHELAN
Tawny Johnson

MICHAEL and VICTORIA PINDER
Randy Ansel

MARKL PRESTON
Nany Prestigiacomo

JOEY RANKIN
Matthew Hogsed
Tracy Mielke
Todd Shinkle

CHRISTINE RATZ
Kate Oshima

ASHLYNN RHODES
Shawna Rhodes

ALDEAN CRAIG SHARP
Rex Gary

KESLEY SHUROS
Mom and Dad
Bear Creek Cabins LLC

MASON SMERDEL
Bernadette Demoura
North Coast Litho
John and Karen Terry

JAMES and LINDA SMITH
Robert and Aline Ficken

JORDAN and ZACHARY ST. GELAIS
Sylvia LePage

MICHELE and LAUREN SURREY
Marion Rissman

ADAM TAYLOR
Maryon Williams

MARY KAY TENSING
-In honor of her birthday
Terry and Jill Parsons

REX TIMKO
Anonymous
Amy Snyder
MaryAnn Snyder

SAMMIE TRUSZKIEWICZ
Matthew De Peri

JOANNA VANMETER
Patricia Van Meter

NOAH VANHOUTAN
Mom and Dad

NOAH and LAINE VANHOUTAN
Madilyn Abernathy
Scott and Cynthia Tinervia

LUKE and RACHEL WATSON
Allen and Cindy Pate
William and Jackie Richards

NICHOLAS WELLNER
Mom and Dad

IN MEMORY OF:

ALLEN ALLION
Andy and Jenni Betz

CATIE ALLIO and HONOR OF ANNIE ALLIO
Carol Adams
Dennis and Teresa Adler
Anonymous
Peter and Nancy Ayers
Kenneth and Christine Babcock
Brent and Dawn Baird
Catherine Barri
Rajkumar Batra
Lee and Lidia Becker
John and Mary Boss
Robert and Wendy Brindley
Marilyn Butler
Lanz and Petra Camacho
Paul and Denise Cantrell
Ruben and Sherrie Corona
Stephen and Toni Coughlin
Dan and Andrea Crimmon
Leonard and Iverna Crocker
Royce and Karen Cunningham
Fred Daniels
Joan Donohue
RA and MM Easton
Sharon and Gary Eberle
Jeffrey and Joanne Erickson
EthosEnergy Field Services, LLC
Helen Fahey
Melvin Ferro
Carl and Janice Fowler
Flavio and Jean Gomez
James and Sonya Grant
John and Janine Grenham
PM Griffiths
Michael Hand
JL and DE Harris
John and Floy Harris
Julie Haynie
StevenHeisinger
Roberta Hescock
Aaron Johnson and Deborah McCrimmon
Lawrence and Claudia Jones
Russell Jones
Helen Kirkpatrick
Demijan Klinc
Charles and Georgina Kretz
Thomas and Cheryl Lenz
John and Priscilla Limneos
Don and Barbara Long
Michael and Cynthia Lucero
Donald Maddison
Sean Maddison
Irene McCarley
Kevin McGreevey
John and Lydia McKenzie
Richard and Mary McLinden
Thomas and Margaret McWilliams
Lisa Nicholas
Christine Pappas
Richard and Sandra Pascoe
Ruth Plunkett
Gerald and Jerelyn Popke
Manjit Purewal
Tyler and Adrienne Quinn
John and Janis Rankin
Cathy Raymos
David Reeves
Michael Renkoski and Rita Reeves
Charles Roberts
Albert and Cheryl Rogers
Livio and Karen Rossi
Rose Schmid
Thomas and Patricia Schneider
Janet Schroder
Edwin and Frances Simpson
William and Janice Spillane
Lena Stell
Kenneth and Karen Stockton
Sherry Stofle
Suisun Lodge No 78 IOOF
Charles and Sheila Thompson
Waletr Tibbet
Donald and Georgia Visconti
John and Virginia West
Robert Willse and Joan Marquand-Willse
Susan Wolfram

CATIE ALLIO
Mom and Dad
Necie Mize
Darlene Townes
Donald and Georgia Visconti

KARI ANDERSON
Paul Kozar
Kenneth and Denise Prohaska

CURTIS ANTHONY
Paul and Elise Anthony
Charles and Nancy Kapper

SAMANTHA APODACA
Cheyenne Quick
Tracy and Jennifer VanHoutan

HILDA BAYHI
Valta Hartstern
Charles and Wanda Leffler

CARL BERGAM
Darrell and Dorothy Bergam
Ed and Linda Bodenlos
Lisa Boyle
Patricia Boyle
Frederick Bryson
Jason and Christy Byle
Jodi Croy
K Faller
Linda Funk
Thomas and Kimberly Green
Daniel and Sabrina Guilliaume
Joseph and Patricia Holden
Laurence and Katie Hoover
Sandy Hunter
Dean and Shelly Johnson
Wayne and Susan Keezer
Steven and Sonya Kraski
Grace Meno
Michael and Susan Parker
Scott and Rebecca Parker
Kevin and Kathleen Parra
Russell and Lori Stach
Mary Thornborough
Craig and Lisa Willis

CELIA BETZ
Adam and Vicky Betz
Tim and Jan Betz
Sandy Ferguson
Sharon Garver
John and Sandra Gills
Jill Kilbourn
Edward and Linda Midkiff
James and Mary Morrison
Veronica Ramirez
Holly Schmidt
Chad and Sandi Sellers
Rodney and Rosemary Tolliver
James Vitela and Leslie King-Vitela
Sara Walker

LYNN and LESLEY BLAKE
Susan Graveline

AMY and MICHAEL BOER
Jeff Howard

AIRON BOLEY
Mom and Dad
Robert Boley
Donna Goff
Debbie Knight
Mike and Tara Rawson

DANIEL BREUER
Dad

JESSIE and MARY LOU BUSHLEY
Irma Roy

ZICHAELA CAFFEY
Jimmie and Bobbie Stanfield

LULU CALDERON
Daniel Calderon and Katarina Vinegrad

CASEN CAMERON
Anonymous
Aunt Flossie's Cupboard
Katrina Blecha
Beverly Brown
Corey Eitzmann Trucking, Inc.
Patricia Gunn
Elizabeth Harrington
Michelle Killinger
Verna Kirchhoff

Kelly Kottmeier
John and Joyce Kroll
Michelle Laneave
M & R Bookkeeping and Tax Service
Ulinda Minatel
Shannon Moriarity-Eads
Heather Paterson
Reid and Elizabeth Polome
Nancy Prestigiacomo
Tracy Purcell
Abigail Rivera
Saathoff Construction LLC
Schultz Diesel LLC
Anthony Schultz
Brian and Erin Schultz
Howard Schultz
Amanda Shea
Tamatha Sponaugle
Antonio and Carmen Suarez
Superior Bowl
Superior Insurance Center, Inc.
T & R Electric Supply Co., Inc
Justin and Barbara Thompson
Tracy and Jennifer VanHoutan
Tyler and Megan Williams

MICHELLE CARLSON
Mark and Kathleen Carlson
Donna Crawford
Jeffrey and Linda Frericks
Stanley and Antoinette Kropen
Peter Kuhlmey and Michele Hussli
Michelle Schultz
Juan and Victoria Uribe

TREVOR CASTLE
Betty Jo Eaton

HANNAH CAULFIELD
Dad and Lori
Amy Caulfield
Cindy Schaller and Brenda Desena

CARMEN CEO
Paul Giansante
Hislop Family Foundation
CNY PGA Foundation
Kenneth and Frances Watkins

CARMEN CEO and SYDNEY CEO-COOLIDGE
Jennifer Bryan
Michael and Margot Carlebach
David and Theresa Clark
Von Connell
Jane Ferrara Memorial Scholarship
William and Elena Keller
David Keon
Elisabeth Miller-Fox
August Sinicropi
Richard and Sharon Tyler

ALLY CHANCE
Mom and Dad
Charles and Rose Chance

JO CHERRY
Don and Ruby Anderson
Samuel Morris

ROBERT CHESTER and CAROLANN YODIS
Florence Yodis

ANN CHOROMANSKI and HONOR OF
DANIELLE and HOLLY CARBREY
Donald and Joan Berra
Holly Bird
William and Sharon Cozort
Steven and Darlene Feder
Daniel and Patricia Gallardo
Gerald and Carole Gassel
Donna Gerlock
Robert and Melinda Hawley
Mark and Margaret Kuberski
Oliver and Helen Lerch
Roland and Marie Martir
Myrtle McClintock
Donald and Clementina Morgner
Dale and Lee Naas
Paul and Carolyn Proost
Kent and Kathleen Smith
Thomas and Susan Miltenberger
William and Mary Waddell
Jane Wendling

DYLAN CLASPILL
Valerie Mobley

RYAN COOPER
Robert and Glenda Cooper (Corky)

KEVIN COPOUS
Kenneth and Karen Copous

MATTHEW CRIMMINS
Denielle Townsend

ETHAN DAVIES
Anonymous
Nikki Ehrich

MARIAH CRAWFORD
Melanie Rollo

MEGAN DEPEW
John and Alice Brockway

KANE DEGEORGIS
Anonymous
Christian and Davis Attys.
Doris Davis
Judith Fulmer
Anna Green
Lisa Meier
Jeff Mitchell
SpringBrook Behavioral Health System
Tracy and Jennifer VanHoutan
Krista Wix

CHAD DOVEL
Mom and Dad

EMILY DUGGER
Steven and Amy Summers

PETER EDWARDS
Douglas and Mindy Morack

EDWIN ELLEFSON
William and Joan Carlson

CHRISTOPHER ERB
Jennifer Carroll
Timothy and Jennifer Fuller
Amy Peiffer

KATIE FEYERSON
Sherise Kauffman

FRAYA SUSAN FIELDS
James and Jayne Fields

THOMAS FLYNN
Jeffery Seelnacht

THOMAS FLYNN and MICHELLE CARLSON
Margaret Eberle and Janet Shine
Timothy and Kathryn Gasparich
John and Catherine Kent
Kelly and Holly Kost
Dirk and Florence Zaagman

MELISSA LYNN FROIO
The Melissa Froio Foundation

SARA GEDEON
Tomas Gedeon

JR GODFREY
Robi Lipscomb

KERRICK and CHRISMOND GOLL
Beverly Goll

DREW GRADY
Linda Hanley
Jalen Mortimer

GREGORY GREEN
Nolan and Mary Bottorff
Wesley and Darlene Bradshaw
Danny and Jane Deshong
Dena Devall
Loretta Earl and Lori Grace
Phil Debbie and Nola Eaton
Darrell and Barbara Galliher
Larry and Julie Greathouse
Charles Heilers
William and Ruth Horstman
Susan Kloss
Ray and Ronita Knarr
HL Lawson
Stuart Mason
Teresa McLeland
Collette Mills
Susan Niccum
Gary and Kellyanne Pelkey
Heather Reedy
Robert Rigney

John and Ann Ritz
Doris Smith
Patrick and Michelle Sullivan
Scott Tuttle
Donald Walker

COURTNEY GUNTHER
Melton and Marilyn Frederick

KOURTNEY DANIELLE HARMON
Thomas and Diane Fogle
Shana Sumner

MATTHEW HARRELL
Lise Ciancio

MEGAN HARRIMAN
Thomas and Janet Gallenstein

STEPHEN HATCHETT
Joanne Howe

MACKENZIE HEEMEYER
Anonymous

LIAM HEFFERNAN
Tracy and Jennifer VanHoutan

AUSTIN HEIN
JC and Linda Antal
Robert and Audrey Fink
Doris Glatz
Heart Of America Chapter BDSRA
Ron and Lugine Hein
Dale and Debra Linneman
Dean and Crystal Linneman
Douglas and Joanna McDowell
Michael and Janine McGovern
Carl and Vikki Schwartze
Donald and Marie Scruggs
Todd and Kimberly Zellmer

TY COLTON HICKS
Group 33 Inc

EZEKIEL HOLT
Todd and Becky Buchholtz

PHILLIP and ELIZABETH HOOVER
David and Robin Herzog

CHARLOTTE IANNI
John and Patricia Bridges

BOB IRELAND
Michael and Nancy Diefenderfer
William and Patricia Dixon

CHROSTOPHER ISNARD
Mom and Dad

JAMIE JERSHA
Donald and Marilyn Blank

ELIZABETH JOHNSON
Mom and Dad
Carol Marshall

HAYLEY JOYCE
David and Angie Bethel

DANIEL KERNER
Frederick and Eleanor Brosio

ASHLEY KIEFER
Wayne and Trina Kiefer

JULIE KLEE
Mom and Dad
Deborah Kelley
Howard and Susan Schub

ED KULP
Donna Patane

NOAH LACY
Jerry and Ann Gieseke
Richard and Sandra Wilton

JUSTIN LAVEN
Mom and Dad
Sandra Connor

CHASE LEHRMAN
Paul and Ellen Ferraro

NOLAN LEIS
Mom and Dad
Harry Beal
Stanley and Carol Clements
Jerold and Karen Leis
Bernard and Vicki Meinertz
Jim and Jill Thompson

KEVIN LUMM
Maugansville Ruritan Club
Atsuko Sanders

JACK MANISCALCO and HONOR of MAKAILA MANISCALCO
Anonymous

BLAKE MASHBURN
Sheila Tillman

LINDLEY MATTHEWS
Thomas and Judy Murphy

RYAN MAYNARD
Mom and Dad
Chris and Margaret Kuffenkanm
Richard and Billie Myler
Oscar Richie
Tracy and Kelly Woodard

ROBBIE and STEPHANIE MAXIM
Madeline Stone

JONATHAN MCCOLLUM
Anonymous
William and Peggy Dexheimer
Debbie Henderson
Curtis Kennedy
Evan Landrum
Alan Rubenstein
John Thomas

Jeffrey and Alison Thompson
Al Walker

CHRISTOPHER MCDONOUGH
Catherine Hester
Todd and Kimberly Zellmer

LEAH KATHRYN MCFARLANE
Anonymous
Barbara Boland
National Fuel Gas Distribution Corporation

JAKE MEDLEY
SE Abbey
Jane Alred
Gail Baker
Ted and Jo-Anne Beam
Lee and Lynn Bledsoe
Sydna Breazeale
Sandra Clarke
Robert and Jennifer Crouch
Robert and Phyllis DeFord
Jeffrey and Melanie Evans
John Fannin
Elaine Francis
Kerry Glidewell
Theodore and Melody Hainline
Sarah Halter
Clark and Carol Hamilton
Nancy Hearn
Ron and Kim Hetrick
CS and JR Holley
Sabrina Hollingsworth
Thomas and Louisa Isaacs
Jeffrey and Laura Jacqmein
Rory Jenkins
William and Heather Johnson
Jeffrey and Julie Kaufman
Kingsland Cable TV/Kings Bay Communications, Inc
Lakewood Presbyterian Preschool
Lakewood United Methodist Church
Land Chiropractic and Sports Clinic, LLC
Anne Lanser
Christian and Elizabeth Leavitt
Gordon and Judith Litt
Robert Mack and Harriet Thomas
Robert and Heather McKee
Cynthia Morphew
Kevin and Karen Pacciano
Todd Perkins
Brian and Tamra Smith
Meredith Smith
James and Cecile Srodes
T Montgomery Salon
Toasties Antiques Inc
Tracy and Jennifer VanHoutan
Katie Weiss

JOEY and BILLY MILANI
John and Marilyn Groome
Joan Karl
John Newby

HUDSON MIMLITSCH
Melissa Fields

CHARLEE NELSON
Christine Vasquez

KAREN NEWTON
Robert and Joann Newton

ZACHARY NOORDHOEK
Greta Noordhoek

NATHAN OLIEN
Robert and Jeannie Paris

DANNY ORTEN
Gerald and Lynne Flynn

DANIEL ORTLAND
Mom and Dad
The Bar Method Ridgewood
Leonard and Bruna Dietz
Jack and Joan Kisch
Raymond and Elizabeth Maniaci
Carol Swarbrick

LAUREN PARKER
Chad Hsu

TAMMY PATANE
Vincent and Grace Parenti

RAYMOND PECORARO
Marion Rissman

SARA PFALLER
Kathlyn Hames
Kenneth and Gloria Kern
Benedict and Luanne Pfaller

MARCY, MINDY and MICHAEL PINDER
Joey and Debra Heffner
Martin and Cynthia Kline
Robert and Susan Lehr
William and Pat Pugh

JOSHUA POWELL
Frederick and Kathleen Powell

SHIV RANA
Mom and Dad
Erica Rose
Jayendra Singh
James and Elaine Soya

SUSIE RODE
Sharon and Jennifer Marcus and Tara Armstrong

SKYLER ROWE
Jacob and Jaime Crawford
Terrie Rhoden

JIM SCHWARTZE
Carl and Vikki Schwartze
The Natey Foundation

KORRY SHARP
Cindy Kelley

KORRY and RACHAEL SHARP
Timothy and Ginger Dunne
Marcus and Cathy Harris

ROY SIMONSON
Leroy and Virginia Simonson

LINDA SIVULKA
Kenneth and Jacqueline Jurkowski

DYLAN RAY SMITH
Laura Blahovec

JAMES SMITH
Marion Rissman

ERIKA SPAIDE
Jennifer Cano

JESSICA and MATTHEW STOCKWELL
Mark and Sally Stockwell

BROXTON TAYLOR
Flexground LLC
Frank and Ann Gennario
Cheryl Johnson
Ryan Orr
Cesar Sanchez

EMILY THOMPSON
Bonnie Jo Thompson

VIRGINIA TOLLIVER
Alice Bunning

BRADLEY TYLER
Mom and Dad

ALI VISE
Beverly Barrett

EZEKYIEL VONDERHEIDE
Tracy and Jennifer VanHoutan

BRITT and JORDAN WATSON
Jerry and Carole Kear

FAITH and PAUL WEISS JR
Paul and Norma Weiss

TRESSIE WELLS
Mary Wells

CAROLYN WILHELM
Chysa Key
William and Judith Leahy

ANTHONIUS WITKAMP
Arnold and Tinie Vanderhelm

CHELSEY WORSTER
Jane Daye
Ann Hold
Paula Worster

DANIEL YANAK
Les and Debbie Ham
Steve Sweitzer and Jani Selfridge

MADDIE ZELLMER
Louis and Beverly Ferlo
John and Sally Keating

DANIEL YANAK
Les and Debbie Ham

PROGRAMS, SERVICES & RESEARCH:

Joe and Kathy Allio
Anonymous
ArcelorMittal Matching Gifts Program
Armstrong, Ronald and Debra
AT&T/United Way/Employee Giving Campaign
Varoujan Baltajian
Bank of America Charitable Foundation
BDSRA Canada Chapter
BDSRA Heart of America Chapter
BDSRA Metro NY/NJ Chapter
BDSRA Midwest Chapter
BDSRA Ohio Chapter
BDSRA Southeast Chapter
Brock and Ellie Benroth
Beyond Batten Disease Foundation
Heidi Bigelow
BioMarin Pharmaceutical Inc.
Thomas and Cecily Bow
Kurt Bruno
Gerald and Mar Lou Brytowski
Joseph and Rita Burns
Everett Butts
Ann Caldwell
Calwest Ltd
Capital One Card Lab Connect Program
Linda Cash
Chevron Humankind
Mike and Dawn Collins
Dennis Coyne
CSX Transportation
Fred Daniels
Marguerite M Delhey
Donald and Victoria Doty
Drew's Hope
Cheryl Dunham
The Easter Foundation
Kim Edwards
Rob Ell
Joan England
Susan Erick
Gail Falk
Eric and Lisa Faret
Daisy Ferreira
George Fuller
Robert and Laura Fussell
Scott and Tara Gair

Gardner Denver Inc
Paul and Patty Gauci
GE United Way Campaign
Rob and Chris Geer
The Giving Campaign/Allstate
Global Impact
Goshen Local School District
Tiffany Grimberg
Sharon Guinther
Marianne Hartz
Michael and Margo Harvey
Chris and Wendy Hawkins
Misty Heaton
Ron and Lugine Hein
Mary Jo Henry
Hergott Enterprises Inc
Scott Hokenson and Lisa Monson-Hokenson
T and J Holecek
Honeywell International Charity Matching
Hospira Employee Giving Campaign
Jeff and Amy Lombardi
Robert Jensen
Jim Jimenez
Jacqueline Judah
Amelie Kelly
Danielle Kerkovich
Larry and Jean Killen
Benjamin and Rita King
Wayne and Ida Lampe
Linkedin
Dave Lippert and Margie Frazier
Mary Lomtong
Janet Maimbourg
Naomi Martinez
Carolyn McMahon
Merck Foundation
Meyers Aerial Service, LLC
John and Madeline Mitchell
Timothy Moeller
Morgan Stanley Annual Appeal
Philip Morisey
Nina Morrison
David and Debra Mussmann
Lucille Muth
Nationwide Children's Hospital
Jeff and Catrina Nelson
James and Carol Neuhaus
Diana Newcomb
Jeff Nichols
Orsini Pharmaceutical Services, Inc.
Partnership for Cures DBA Hope 4 Bridget
Partnership for Cures DBA Noah's Hope
Joan Patti
Doug and Ann Paul
Berwyn and Betty Petersen
Mark Pfeifer
Pfizer, Inc.
Shawn Principi
Frederick and Bernadette Prozzillo
D and S Randolph
Martha Reckdahl
Dean and Yvonne Reid
Riverview Baptist Church
Donald and Cynthia Robbins
Gloria Rowan
Donna Roy-Molitor
Scott and Lindsay Rugg
Gail Salva
Sanford Health
Sempra Employee Giving Network
Seville Financial PC
St. Mary's Catholic Club Inc.
Sally Steward
Hunter Stockton
Kenneth and Karen Stockton
Superior Spirits
John and Kirsten Swindall
Charlie and Hayworth Szymborski
JT Tammaro
Stephen and Bonnie Thompson
Thompson Reuters
Tobi Tse
UBS
Tracy and Jennifer VanHoutan
Brent and Heather Voight
Wells Fargo Community Support Campaign
Florence A Yodis
YourCause, LLC Trustee For Hewlett-Packard

Donations from these events were made to BDSRA through August 31, 2014:

4th Annual Ryan Kennedy Memorial Charity Ride
-In memory of Ryan Kennedy and Chris Erb

9th Annual Asher Bash
-In honor of Asher Nikolajevs

11th Annual Kevin's Fund Golf Tournament
-In memory of Kevin Lumm

Ascential Acupuncture
-In memory of Celia Betz

Davies Family Garage Sale
-In memory of Ethan

Heart of America Chapter BDSRA Trivia Night

Run the Creek
-In honor of Brandon and Jeremy Hawkins

T-shirt Sale
-In memory of Chelsey Worster

Approximately $26,301 was donated to BDSRA for research and services.

Please direct any questions or concerns regarding this list to Tracy Kirby at tkirby@bdsra.org or (800) 448-4570, ext. 13. Thank you for your continued support.